

COMMUNICATING TOGETHER

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AS ABILITIES CHANGE

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Changes Across the Decades

SHIRLEY McNAUGHTON

What a difference! Prior to the forties, one's motor capabilities were used as the measuring stick for one's mental abilities. In the fifties, if you were lucky enough to have a service program at all, you had speech therapy — whether or not it accomplished anything! In the late sixties and early seventies, AAC was introduced. Now there is need as described in this issue by Eugene McDonald, a speech language pathologist and psychologist with many decades of experience, to remind professionals that we must focus on *augmenting* the child's unique manner of communicating rather than emphasizing *alternative* systems. In thinking about these matters, the editors of **Communicating Together** decided to dedicate an issue to the theme "*Changes across the decades*".

As the editor who volunteered to be responsible for the content for this issue, I, of course, thought back to the persons with one or more decades of experience in AAC whom I knew would provide **Communicating Together** readers with a range of thoughtful perspectives. They are all colleagues whose observations and insights I have valued throughout the years, along with my associations with them. My invitation to submit an article asked them to look back and share their insights, from their perspective. Their articles reflect many different views of former years. I hope you will find them both thought provoking and informative.

This Issue

Barbara Rush, who has written the feature article, gives an excellent first-hand account of her experiences as a teacher and consultant during the last three decades. Her observations illustrate well that we have yet to achieve a balance between adequate language, literacy and communication instruction and support, and the socialization and community involvement provided by educational integration. The pendulum has swung from a goal of specialized segregated classes of the seventies to the integration of every child at an early age in the nineties. As Barbara has pointed out, the swing may have left many children without the language and educational base they need in order to benefit from the programs of their nondisabled, speaking peers.

"With AAC technology comes an emphasis on how to use it, not on the communication system it uses or the language base that is required for literacy."

"The bottom line is that unless there is an environment in which attempts at communication are encouraged, the skills involved will not develop. Something has been lost."

Barbara Rush, page 6

Eugene McDonald also offers a valuable perspective as one of the pioneers in the AAC field. I remember in the mid seventies when Eugene McDonald first warned professionals against focussing all their time on

syntax and the structure of language. He argued eloquently that attention should be directed toward *functional* communication, not purely form. He has watched many a pendulum swing and shares his perspective on what he perceives as the current one, with the wisdom that can come only with experience and caring.

In his article, Eugene McDonald refers to one of the first conferences on AAC issues that was organized by Gregg Vanderheiden, the current Director of the Trace Research and Development Center, Madison. Gregg Vanderheiden is a valued colleague who has been involved in AAC since the seventies. I remember the initiatives taken by him through the publication of the *TRACE Resource Book* that was based on a series of TRACE Workshops held in 1975 in Los Angeles, Chicago and Boston. Eugene McDonald and I were both presenters in those workshops. As I look back, I realize Gregg Vanderheiden was obviously choosing presenters who could bring different types of experiences. Eugene McDonald provided the perspective of a speech-language pathologist who had worked for many years with children with cerebral palsy and who had pioneered work on word and letter communication boards. I provided the perspective of a teacher with only seven years experience with children with cerebral palsy, but one who was enormously excited by our team's accomplishment and the innovations made possible by Bliss-symbols.

Unfortunately, Gregg Vanderheiden had to decline my request to write an article for this issue due to his many other commitments. He did however share in a letter

some of his memories of the early seventies. He recollected that he coined the term "*augmentative communication*" in the seventies as a strategy to address the concern of speech language pathologists that the use of communication boards with their clients was admitting defeat for speech acquisition. He wanted to emphasize that the AAC system was *augmenting* the communication capabilities the individual *already* had.

Eugene McDonald provides an insightful update on that issue. It is interesting that there may still be cause for concern. Speech acquisition may indeed be put at risk, but not for the reasons envisioned by professionals in the seventies. In those days, there was concern that the learner would not want to learn to speak. Today, Eugene McDonald sees the child's idiosyncratic attempts at communication being overlooked with attention being placed instead on mastering a synthetic speech device.

In my *Perspective*, I have been influenced by the cohort approach presented by Foot and Stoffman (*Boom, Bust and Echo*, 1996). I have shared my observations of persons closely involved with cerebral palsy through the successive decades of cohorts across this century. Penny Parnes, in her treatment of the theme, recollects the people with whom she has worked and learned through the decades. Penny brings out many of the insights and values she has gained from these people.

The approach taken by Margaret Szilagyi is quite different and interesting. As soon as she heard about the theme of this issue, she told me that a chart she had seen relating to the evolution of man jumped into her mind! You will see how she applied that chart to AAC users in her *Perspective*.

In her first contribution, Alda Steprans introduces us to the life of Steven Hanlon. We are given the opportunity of meeting another special person and learning how he is facing the challenges imposed by an acquired disability. In her section *As Communication Changes*, Alda looks at how nursing has changed across the decades. She describes her learning and identifies some of the best in nursing advancements over the past two decades.

In her section on *Teaching and Learning*, Tracy Shepherd decided to focus on individuals from the *Baby Bust* generation and the challenges they face. She shares her column with a guest writer, David Dame, who has been able, with extensive effort, to get a job. David speaks! Tracy hopes that society will give AAC users a chance at meaningful employment as well.

Geb Verburg looks back and evaluates both our progress and non-progress in AAC and rehabilitation over the past two decades. His position regarding the need to improve our record in applying research outcomes when they can benefit persons with disabilities is very deserving of attention. I have witnessed the situation he describes for over 20 years. Let us hope that, by looking back, we can strengthen our resolve to make changes in the future.

Paul Marshall does his own looking back by describing the changes in society as he has been growing up.

Finally, we have paused in this issue to remember Brian Pamplin, one of our Associate Editors. Brian passed away during the past year. We will all greatly miss his contributions and unique insights.

I am glad we have taken the time to look back in this issue. There is much to be learned by observing what has

gone before, especially in a young field such as AAC where change happens so quickly.

As you will see, the examples in this issue have related exclusively to children and adults with cerebral palsy. It would be so helpful to have a similar description of changes through the decades related to persons who have severe speech impairments as a result of strokes, acquired neurological disorders, or cognitive limitations. We would welcome such articles in a future issue of **Communicating Together** and extend an open invitation should our readers wish to share their experiences through the decades with a different population.

From all the Editors of Communicating Together

Happy 1997! We wish you success in providing opportunities for AAC users to lead satisfying and productive lives in the coming year. Please join us as soon as you can in our new **Communicating Together** venue on the World Wide Web. As we move to the next decade, this is our way of making independent reading available to AAC users for whom magazines and books impose physical barriers. Our address is: <http://www.ahs.uwo.ca/orcn/assoc/comtog>

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Please remember to let us know your new address. If possible, send an address

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Canada, N1G 4W4

The Changing Educational World

BARBARA RUSH



Barbara Rush working with a student

Barbara Rush was one of the first teachers in North America to use AAC techniques with nonverbal children. She is an extraordinarily gifted teacher who has been committed to the education of children who are nonspeaking for over two decades.

It has been my fortunate experience to have been around long enough to be involved with augmentative and alternative communication (AAC) since its earliest days. I have witnessed many changes in communication systems, technology, and educational philosophy since 1970. Most of it has been for the good but I do have some reservations concerning others. This article will review my teaching assignments from 1970 to the present date and the effect that the prevailing methodologies have had on the students' lives.

1970-1979 Assignment: Segregated self-contained classroom located in a medical facility.

We were a teacher, and eight students with multiple physical disabilities. The students, aged five to

ten years, were severely physically disabled and had a variety of communication impairments. Most were cognitively intact with just two low-functioning individuals. As the decade began, our language activities consisted of cutting out pictures from magazines and catalogues and pasting them on cardboard displays to which the students would eye-gaze. It was definitely low-tech!

Our very first breakthrough came with the discovery of Blissymbolics, just being introduced to classrooms in Toronto. The speech pathologist and I scooted down the highway at the first opportunity to see what was going on. We were not totally convinced of the efficacy of the system at first but having nothing else to substitute, decided to give it a try. Thank heavens we did! It literally changed our lives and the learning potential of all the students and those yet to come.

Enthusiasm was sky-high as we discovered exciting opportunities and results together.

We felt like pioneers. Students, teacher and speech pathologist all learning together as we delved into this new approach. We were an informal team as the concept of multi-disciplinary teams had not yet evolved. The work was labour-intensive as no commercial materials were available and all the symbols and displays had to be hand-drawn. Naturally, all materials were designed to meet the needs of individuals. We were urged on by the acceptance of Blissymbolics by our students and their families. Students were now communicating beyond simple choice-making. Blissymbolics, with its pictographic, ideographic, and fully-generative

language properties enabled them to express thoughts, needs and ideas and whole new personalities began to emerge. Enthusiasm was sky-high as we discovered exciting opportunities and results together.

As these students increased their proficiency communicating with Blissymbolics, we came to realize that the nonspeaking group could be identified as a sub-group of the special needs population. A class of such students was formed and we were thus able to devote huge blocks of time to Blissymbolics, language, and communication training. Teacher and student energies were totally directed to AAC activities. AAC was not a separate subject to place on the timetable but an integral part of the entire school day. The learning was intensive but since communication and language development are central to everything else a child will achieve in life, we considered it worthwhile, if not essential. We became a community of native speakers and learning sped along the fast track. It was so easy to deliver highly specialized services to this concentrated group. The students from this era made monumental gains, changing their lives from being passive recipients of care and instruction to active, responsive participants in life at school and home. A tremendous bond developed between members of this group with friendships that have extended to their adulthood today. They still share the strong sense of identity and worth that we were able to establish in those primary classrooms.

In 1977, sign language was added to our 'bag of tricks'. We decided to use Signed English as it incorporated a one-to-one correspondence with the English word. As such, it was a great aid to literacy activities. Signing is difficult for students with motor impairments and many approximations had to be accepted. Students often created gestures and idiosyncratic signs for themselves. We found signing to be a powerful adjunct to

our total communication programme. With signs, Blissymbols, pictures, and words, we were able to use a multi-modal approach — see it, hear it, say it, do it, feel it. Powerful!

The total communication approach enabled us to foster language development and communicative social interaction and to emphasize metalinguistics in all language activities. Blissymbolics with its indicators and generative properties, and signing with its morphological markers, are ideal tools for teaching students about language itself. I well recall one precocious six-year old happily using the terms ‘adjective,’ ‘noun,’ ‘past/future tense verbs,’ ‘regular/irregular plurals,’ with an astonished principal. Most grade one students, although they might use such language forms appropriately, do not understand the labels and functions of these terms. The demands of learning Blissymbolics and Signed English well require that these terms be labelled, learned and used. It is my personal conviction that modified use of augmentative techniques, particularly Blissymbolics and signing, would be of great benefit to verbal but language-impaired students and those learning English as a second language.

This cohort of nonspeaking children had some wonderful experiences together. They learned so much about language, communication, themselves, and the world around them. I doubt very much that this level of learning and progress could have been possible without the community of native speakers that existed. We are all familiar with the popularity of French Immersion classes. Parents and educators recognize that language can be learned faster and easier when one is surrounded by those using the same language throughout the day.

1980-1989 Assignment:
Augmentative Communication
Resource Teacher serving segregated self-contained classes in both segregated settings and in regular schools.

With the overwhelming success of the initial Blissymbolics and later total communication classrooms, enlightened administrators decided to extend this approach to other communicatively-impaired students. In the early years, we added developmentally-delayed youngsters to our population base and by the mid-80's had included speech and language impaired students. 1988 saw the first communicatively-impaired student in our district totally integrated into a regular classroom in his home school. As a resource teacher, I was able to reach out to students and teachers from junior kindergarten through to grade 13 throughout our educational system. There was never enough time, money or resources to do the job properly but we tried. Delivery of services was co-ordinated but instruction became splintered. Since total communication is not curriculum or programme bound, it is an approach that needs to be available throughout the educational setting. Thus it was extremely difficult to effect the necessary changes.

The total communication approach again proved effective but progress was not as dramatic as with the high-functioning, native group. Only facets of the Blissymbolics and Signed English programme were appropriate for intellectually-impaired students. Picture sets provided the best means for labelling and choice-making. This group proved to be less motivated to learn how to communicate and take control of their own lives. They were certainly not interested in carrying around a picture and/or symbol display. To overcome this hurdle, we came up with theme boards that were placed in various locations.

Multi-disciplinary teams were now becoming the norm. Occupational therapists and computer technologists were able to facilitate better access with the many computer systems and software that were thrust upon us. The

AAC population evolved into two natural divisions; the severely physically and/or intellectually impaired group relied on signing, picture sets and a few pictographic Blissymbols, and the more able students were forging ahead with all forms of total communication, technology and voice output systems.

Now that many of these students were located in regular schools with either partial or total integration, literacy issues became even more important. However, most of them did not have the language base that the original total communication classroom had provided. AAC students in this decade received instruction either from agencies off-site, piece-meal from a resource teacher, or intermittently from the non-AAC trained classroom teacher. Often they were the only AAC user in the classroom or in a small group in a mixed setting. There was no community of native speakers, no emphasis on metalinguistics, and time had to be shared with many other subjects. It proved impossible for regular classroom teachers to find the time to develop all the requisite specialized AAC skills in systems and adaptive technology or to provide one-on-one instruction to AAC students.

The one huge advancement for this time was social and academic integration. Integration issues were at the forefront of the advocacy movement. It was gratifying to see the closure of special schools and the gradual acceptance of special needs students in regular schools. The trade-off for decreased AAC instruction was social interaction and language learning in the ‘real world.’ It now became possible for AAC users to learn and use

language in functional, naturally-occurring situations with mature language-using peers in their environment. In addition, both disabled students and their able-bodied peers had opportunities to develop appropriate social skills together. Although I may regret the loss of AAC-speaking communities, the improvements in the attitudes that non-disabled peers began to develop for exceptional students, and the building of positive relationships and friendships between peers cannot be dismissed lightly.

1990-present Assignment: Segregated self-contained class in regular school.

I found myself at the beginning of this decade right back where I started: teaching multiply-disabled students in a self-contained classroom. However, much had changed. Classrooms in the medical facility had been abandoned. The regular school placement opened up many new language learning opportunities; gym, lunchroom, assemblies, school trips, buddies, integration. It was exciting all over again.

My students were from six to twelve years old and all were nonspeaking or low-verbal. Four were high-functioning and heavily involved in Blissymbolics, signing, and literacy activities. The others were less able and relied more on gestural cues, tangible symbols, transition cues, and picture sets. Every student had access to computers and three used voice output devices. High tech was in full swing.

Since full integration and educational placement in the 'least restrictive setting' were high priorities, we placed all our students in regular classrooms with age-level peers for portions of the day. Our classroom became more like a communication resource room with the ideal day split 50/50 with regular class integration. As students' communication skills improved to the point where they could

learn and manage in the regular classroom, their integration increased. Over a period of three years, we saw the transfer of all the high functioning students into regular classrooms. Along with these developments, changes in placement philosophy saw most special needs children placed in regular junior kindergartens with specialized services provided by itinerant resource people. Nonspeaking, physically challenged students were no longer placed in the total communication classroom. These settings were only for the lowest-functioning and medically-fragile students. An intensive total communication approach was no longer appropriate.

At the present time, my class has five students, all severely physically disabled and developmentally delayed. We use a few gestures, signs and picture sets for labelling and choice-making purposes. But since all are at the pre-symbolic stage of communication, we do not get into any serious literacy activities. Integrated AAC communicators elsewhere have a much more difficult task. They are not getting the metalinguistic grounding they need and they have no flourishing AAC models to follow. There is a lack of user groups with which they can identify. Too much is being expected of the regular classroom teacher. Recent economic restraints have led to a reduction in resource services.

Yet educators are now expected to meet the social, academic, and therapeutic needs of more and more exceptional students. The AAC resource people we have are exemplary specialists but their task is daunting. They have to provide their services according to the consultation model which is certainly not enough to train teachers and instruct students. Teacher energies are further splintered as curriculum demands are so heavy. In addition, the AAC user moves on each year to a new teacher and the whole training process has to begin again. However, no one can deny that the social

benefits of integration have greatly benefitted all special needs individuals. Whether they outweigh the academic and communication needs of *certain* students is a debatable point.

Summary

In the over 25 years that I have been working in the field, AAC has come a long way. It is now widely accepted by professionals and consumers alike. As I near retirement, I see that the AAC industry is healthy and still evolving. Perhaps the concerns I have today are merely rueful comparisons with my almost idyllic introduction to AAC in the 70's. I do worry about the loneliness and isolation of some AAC communicators in large classrooms and a tendency to rely too heavily on technology in some settings. With AAC technology comes an emphasis on how to use it, not on the communication system it uses or the language base that is required for literacy. Computers are wonderful and I could not live without mine! However, communication is a social act and I don't believe that a computer or voice output device can ever replace down-on-the-floor, eyeball-to-eyeball contact with a student involved in learning and manipulating language symbols. Less emphasis on language instruction and generative graphic systems such as Blissymbolics has led to a lack of metalinguistic training. Today we see many more professional training opportunities and multi-disciplinary teams are fully recognized. But now we can't afford to access these services and our AAC population is scattered throughout the school system. It is very difficult for AAC specialists to deliver services to such a widespread population group. The bottom line is that unless there is an environment in which attempts at communication are encouraged, the skills involved will not develop. Something has been lost.

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Brian Pamplin 1952 - 1996

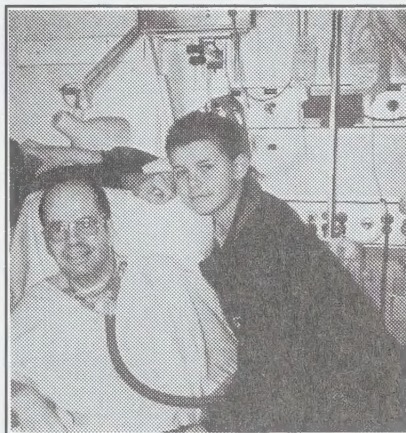
I was just ready to submit my article for this edition of **Communicating Together**, when I learned of Brian Pamplin's death. I needed to go to the funeral home to say good-bye to him, to really understand that he would no longer be there. It was good to see him looking so peaceful, not struggling to breathe or to find a comfortable position, but it still hurts to think that I will not be able to share any more time with him. I will miss that sparkle in his eye and his wonderful sense of humour and understanding. He has left an emptiness in me that I cannot describe, despite the fact that I have so many other wonderful patients and friends that I care about. I feel very fortunate to have known him, to have been inspired by him, to have had the opportunity to learn so much from him. Thank-you Brian!

I know that there are many other people who felt blessed by knowing Brian. I extend my deepest sympathies to them all, but especially to Bernice and Gregory, who tried so hard to always be there for Brian, despite all those other pressures of daily life. He loved you so very much!

ALDA STEPRANS

"I understand why we are called 'patients' because 'patience' is a required virtue of people who are so dependent on others to help with the functions that through most of their lives, they took for granted."

Brian Pamplin,
Communicating Together, March 1996



Brian Pamplin with his son Gregory

"If I can't be with Gregory, it is better that someone else can."

Brian Pamplin,
Communicating Together, June, 1996

"The biggest thing is having people take the time."

Brian Pamplin,
Communicating Together, June, 1996

Strange, but when I think of Brian, I think of strength and serenity! Perhaps it was the unexpectedness of discovering these two qualities that made my visits with him so rewarding. It wasn't until Alda was in Latvia last year that I began visiting Brian — initially on behalf of **Communicating Together**, but very quickly because I enjoyed being with him. From the moment I arrived on my first visit, *Brian made me* feel comfortable. His quiet determination, sense of humour and interest in new ideas, along with his acceptance of the life multiple sclerosis had forced him to lead were evident every time I saw him — even when energy faded quickly — during his months in intensive care. His perseverance when his communication was not understood (both the lip talking and the eye gaze spelling), the forever twinkle in his eye and the concern for those dear to him, were always there. He was so proud of his son and so caring about the welfare of his wife. I will miss Brian! His courage and generosity of spirit will always be remembered. **Communicating Together** readers have lost an Associate Editor who had much to teach us all! We send our condolences to Brian's family.

SHIRLEY MCNAUGHTON

Learning From the Past

SHIRLEY McNAUGHTON

In looking back personally, I have found that the categories included in the book *Boom Bust & Echo* by Foot and Stoffman (1996) offer a useful structure for thinking about the opportunities experienced by persons who lack functional speech. A consideration of the cohort group into which a person is born and within which he or she grows up provides insights into the professional knowledge base, economic forces and societal attitudes that have influenced all facets of their lives.

The following are a few excerpts from a short history of service delivery for persons with cerebral palsy that I wrote in 1991. I have applied some sections from my paper to the categories of cohort groups listed by Foot and Stoffman.

The first two decades (1900 to 1919)

As late as 1920, nothing was done for children with cerebral palsy. Doctors accepted the attitude of Little, the physician who first identified the condition of cerebral palsy in 1862. According to Little, persons with cerebral palsy were "probably of low-grade mentality and little or nothing could be done to improve their condition" (as described in Schonell, 1956, p. 14).

The Roaring Twenties (1920 to 1929)

Children with cerebral palsy were usually placed in large institutions and typically the diagnosis was "congenital idiot" or "idiot cripple".

The Depression Babies (1930 to 1939)

Near the end of the thirties and into the early forties, new treatment approaches were beginning to be advocated. Some persons — the lucky ones who were able to find informed professionals — began to

benefit. Earl Carlson (1941), a medical practitioner who had cerebral palsy himself, wrote a book about his own life and urged those working with children with cerebral palsy to study the child as a whole and make every effort to understand the development of the child's psychological life. Winthrop Phelps (1938), an orthopedic surgeon, adopted the term cerebral palsy for the condition and described its various manifestations. He sought for a solution to the cerebral palsy "problem" through a careful diagnosis of each individual case, to be followed by physiotherapy of an intensive, specialized kind.

World War II (1940 to 1946)

During this period, considerable interest had been aroused in cerebral palsy. Nonetheless, according to an article written by Jennings (1945, reported in Schonell, 1956) in the *Health Magazine* of the American Medical Association, there were only forty public institutions (including homes for the feeble-minded) that would care for spastics. None of them treated cerebral palsy cases exclusively. Moreover, there were only three private schools in the United States which catered specifically to children with cerebral palsy. In 1944, a day nursery for handicapped children was opened in Chicago.

The Baby Boom (1947 to 1966)

In terms of the services that were available during this period, Schonell (1956) writes:

Every state has a crippled children's agency which, as a public service, is supported by taxes, both state and Federal... while some states such as New York and California have extensive state-wide services for cerebral palsied children, provision in some other states is very meagre.

A number of universities and teachers' colleges were giving special courses in teaching cerebral palsied children and a national organization was established in 1949 in the United States — The United Cerebral Palsy Association. In the fifties and sixties, the medical professionals working with children with cerebral palsy began to affirm that the correlation between motor and mental involvement was not as great as one might expect and that there might be total physical involvement with normal intelligence (Perlstein, 1948).

In a book for teachers, Leaning (1958) commented on the swinging of the pendulum from regarding all persons with cerebral palsy as having a mental defect, to efforts by isolated groups during the forties and fifties to eliminate any association between mental impairment and cerebral palsy. Michael Williams, reflecting upon growing up in the fifties, remembers:

Twice a week my academic pursuits were interrupted. I was sent out of the classroom and wheeled down to the other end of the building where I was put in a small, airless room to await the arrival of the school speech therapist... For me these twice weekly therapy sessions were torture.

Ruth Sienkiewicz-Mercer, born in 1950, had both constructive and devastating experiences, depending on the setting in which she lived. The two State Schools she lived in failed to recognize her intellectual capabilities, diagnosing her as an "imbecile". Fortunately for her, she had the support of a loving family. She lived at home during her early years and was able to spend three and a half years at the Crotched Mountain Rehabilitation Center in New Hampshire, where "Every resident was treated with respect for his or her individual needs."

The Baby Bust (1967 to 1979)

As we enter the late sixties and seventies, I can write from personal experience. Upon joining the Ontario Crippled Children Centre's School as the Kindergarten teacher in 1968, I found children with a full range of disabilities in every classroom.

Hyperactive youngsters with muscular dystrophy, asthma, cystic fibrosis and cerebral palsy, all shared the same classroom. Teaching assistants were not available. The only help that was available was any help that could be recruited from volunteers by the teachers. I eventually developed a pool of over 70 volunteers, each spending a half day per week or per month, but that took three years! There was no specially adapted equipment except standing tables and rolls for children to lie prone on to work on the floor. Children who were unable to speak were not treated any differently from the other children. They just never had any turns to answer or sing or "read".

As I moved up with my class to become their Special Grade One teacher, I realized more and more the additional handicap imposed upon those children who could not talk. Along with an occupational therapist, Margrit Beesley, we asked for time to develop a communication program for these children. The rest is history! We were given permission for an exploratory programme. We formed a team, and, building upon the work of Charles K. Bliss, experienced the joy of participating in one breakthrough after another as our children gained skill in communicating with Bliss. We began training other professionals, and throughout the seventies, Blissymbolics went around the world through the work of the over 8,000 persons we and our colleagues trained.

During this period, our dream was to enable these young people to leave the large institutions and to gain access to regular educational programs. In 1978, our first two students were integrated into regular classes, requiring much persuasion and support on our part!

Baby-Boom Echo (1980 to 1995)

We had to wait for the eighties for the first individuals to leave the institutions. Justin Clark's move into the community (See **Communicating Together**, June, 1996) was likely the most publicized departure, but we witnessed many exciting moves into the community by persons who used AAC.

This period saw the expansion of AAC programs and the integration of many children into the regular school programs. As the eighties moved along, however, we saw the beginning of fiscal cutbacks. In our immediate area of service provision, a much needed and appreciated educational service program sponsored by The Easter Seal Society of Ontario had to be closed. Resources and consultation to educators doing their best to teach AAC users within integrated settings were very limited. The many problems associated with integrating children with specialized needs when sufficient support services were not provided became increasingly evident.

My looking back has made me wonder whether or not we would ever have had the many advancements in AAC if there had not been a *Baby Boom* generation. The persons with cerebral palsy born between 1947 and 1966 created enough individuals in need of communication at treatment centres around the world that professionals and manufacturers noticed them! Once the attention and development began, it continued, even though the *Baby Bust* (1967 to 1979) generation followed and numbers requiring special attention in the late seventies and eighties were smaller.

With the *The Baby-Boom Echo* (1980 to 1995) generation, the stimulus to development continues. I truly hope we will learn from the past. I hope we will try to combine the best from both ends of the pendulum swing to ensure that the special instructional needs are met along with the socialization opportunities that come with integration. There is need for knowledge *and* effort to see that it is applied. The inspiration for both can be found by a blending of new knowledge and technology, with careful observation of what has gone before. Hopefully we will be able to observe, interpret and evaluate past practices that showed potential, but may have been overlooked in our haste to travel quickly onward. There are many programs that deserve revisiting!

A quote from our feature article by Barbara Rush provides a compelling reminder of the essence of communication:

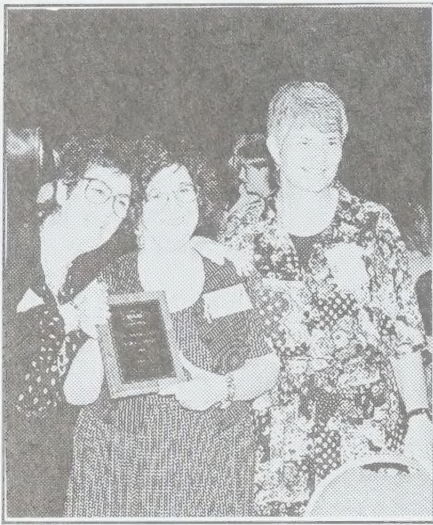
"I don't believe that a computer or voice output device can ever replace down-on-the-floor, eyeball-to-eyeball contact with the student involved in learning and manipulating language symbols."

The Future

And now to the future! In these times of economic restraint, the coming year will have its challenges! An important lesson I derive from my looking back has been the strong impact of the knowledge of professionals and significant others. A lag is to be expected between what those who associate with AAC users have learned and what society is prepared to support. This is why we, who are fortunate enough to have the knowledge, have a tremendous job to do!

References for this article are available on our Web site, <http://www.ahs.uwo.ca/orcn/assoc/comtog> or on request from Sharing to Learn. §

PENNY PARNES



Penny Parnes, with longtime associates, Nora Rothschild and Lynnette Norris, sharing her joy at receiving the ISAAC Distinguished Service Award, August, 1996.

Penny Parnes is now working as an independent consultant. She has filled many responsible positions over the past twenty-five years: speech-language pathologist, Blissymbol instructor and consultant, Director of the Augmentative Communication Service of the Hugh MacMillan Centre (now the Bloorview-MacMillan Centre), Vice-President of the Hugh MacMillan Centre, and president of ISAAC. She describes her experiences over the years and the people with whom she has worked.

It is interesting to think back to my early days in AAC and how the group of people surrounding me affected my thinking and approach to the issues of AAC. As I reminisce and try to project my perspectives, I know that this will sound like a who's who of AAC. It may even be seen as the ultimate in

name-dropping! But, I think it was those people and those times that did influence me. I was very, very fortunate in the people with whom I interacted.

My good fortune began in my first exposure to AAC through Blissymbolics while still a student in the Speech-Language Pathology programme at the University of Toronto. This would have been around 1971-72. Since the application of Blissymbolics only began in 1971, I certainly was an early arrival on the scene. I attended a lecture in Toronto given by Judy Seligman (now Judy Seligman-Wine) and sat enraptured by her description of the use of symbols with children at the Ontario Crippled Children's Centre (OCCC) subsequently the Hugh MacMillan Rehabilitation Centre and now the Bloorview MacMillan Centre. At the same time I became friendly with someone related to a friend of mine, Barbara Kates. She too was on the initial Blissymbol team at OCCC. About this time, a small committee was forming to oversee the development and promotion of Bliss. They were in need of a volunteer speech language pathologist to work with them. I of course was delighted to volunteer. My association with the founders (and near founders) of Blissymbolics continues to this day and they are people who still continue to influence my thinking and approaches.

What that early exposure did for me was to give me a great belief in the strength of teams, particularly multi-disciplinary teams. We had an idea and we were committed to seeing it grow and be accepted. We didn't wait for funding. We didn't wait for all the research results. We

worked very closely with many users. Names that come to mind include Sue Odell, Kari and Ruth Harrington, Paul Marshall and many others. When I hear people today "discovering" the power and benefits of being consumer or family focussed, I wonder, that we never questioned that as being a key component. I think that much of the credit for this approach must go to the team itself, but certainly to the leader of that team, Shirley McNaughton. Those ideas — being committed to a team and to being focussed on the end users — have stayed with me always.

The other thing that I learned from those early days was to have courage. Being a rather shy person, I never would have had the nerve on my own to approach some of the people who were dabbling in AAC at the time to suggest co-operation. Many of the team members certainly had the confidence and the nerve. It was the late 70's and early 80's that we decided it was time to try to get people formally working together. We decided that what was needed was a conference to focus on non-speech communication (this was before the widespread use of the term AAC). We had two very successful conferences in 1980 and again in 1982. The list of speakers was formidable and I don't dare list them because I am sure to leave out some key people. The offshoot of the second non-speech conference was the decision to look into forming an organization. This led to the famous meeting in East Lansing Michigan in 1983 which led to the formation of the International Society of Augmentative and Alternative Communication (ISAAC).

I learned a lot from my colleagues in the late 70's and early 80's about how to deliver services. Along with Shirley McNaughton, Nora Rothschild, Lynnette Norris and Margaret Beesley, I began some programmes focussed on symbols, AAC and technology at the OCCC. Not too much later we also recruited Barbara Collier and Kathy Lee to join us. We were very firm in our vision and in our values. We always kept the needs of the client in the centre of what we did. We knew that by talking together and putting our collective heads together we would develop in the right direction and be able to change course as required. The hours we worked were long, but all of us would say that they were some of the best days of our professional lives. I learned a lot about management from those experiences. I learned that an organization has to take a risk. OCCC in those days believed that there was something worth nurturing and developing in this new field. They gave us the support and the freedom to develop it. I also learned about teams in management. Although for many years I was the director of Augmentative Communication Service program at the OCCC, it was always clear to me that the leadership came from the team. If I ever forgot that, my colleagues were quick to remind me. It was a programme that grew and flourished in that environment.

I have also learned a good deal about the importance of integrating research and education into what we do. In terms of research particularly, I was very influenced by a student who approached me about working with us and doing some of her data collection at OCCC. This of course was Janice Light. I learned early on that, even in research, the client and family must be the focal point. We

need to find out from them what they need and then use our skills and backgrounds to address those needs. We owe it to them to share our results with them. This was so natural to Janice yet so foreign to many of the other researchers I had worked with. I also learned the importance of sharing information in the printed form with as many people as possible. I had always looked at publishing as a more academic enterprise but quickly saw the benefits to the field as a whole of this approach.

We always kept the needs of the client in the centre of what we did.

Technology is another area in which I have learned a lot. I learned again about the importance of understanding what it is you are trying to achieve with technology. Technology must be viewed as a tool to achieve a goal, not as a goal in and of itself. Many of the people who influenced my early thinking in this area were people who were committed to clients. The biggest influence probably came from Fraser Shein with whom I worked for many years in the areas of AAC and later in computer access. Fraser always knew that as an engineer and a developer, he had to keep the client at the centre of this thinking. Again this was an approach that many people in related fields are only now discovering.

I even learned a little about government and bureaucracy. It is hard to believe in this day and age of government cut-backs and downsizing, that a government could actually come across as truly wanting to help its citizens and develop programs to remove barriers for people with disabilities. Probably

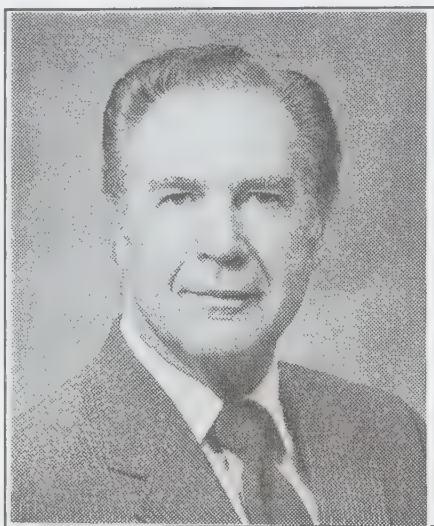
my experiences with the Ontario Ministry of Health's Assistive Devices Program were reflective of the vision and openness of the particular director of that program at the time (Betty-Jean Findlay), rather than of the government as a whole. But the success we were able to achieve in having AAC formally included in the Assistive Devices Program by 1984 and hence funded by the government was groundbreaking. It gave me the belief that if you did the right things and you did them in the right way, anything was possible. I think that I still retain the optimism and faith in people and processes from those days. Although many events of late have challenged this optimism, I hope that I will never give up on it.

Was I influenced by my peer group in starting out in the field? I certainly was! I learned from so many people:

- the important and vital role of consumers
- the strength of teams
- the necessity for management to support risk-taking
- the importance of research with firm values and a focus on client needs
- the importance of a client-controlled perspective on technology
- the role that government can and should play.

I have shared some of the lessons learned and values established from my early days. In looking back, I can see that my learning didn't stop there and hopefully will never stop. §

EUGENE T. McDONALD



Eugene T. McDonald

*Eugene T. McDonald is Professor Emeritus in the Department of Communication Disorders, Penn State University. He served for many years as a consultant in speech pathology and psychology to the Home of our Merciful Saviour in Philadelphia, Pennsylvania, and the Matheny School for Cerebral Palsied Children in Peapack, New Jersey. He is author of **Understand Those Feelings**, (a guide for parents of handicapped children), **Articulation Testing and Treatment**, **Cerebral Palsy** (co-authored with Burton Chance, M.D.), and **Teaching and Using Blissymbolics**. We who were involved in the early Bliss program in Toronto in the seventies will always be grateful for the ongoing wisdom and advice he brought to our team. He has been a wonderful mentor and friend.*

In 1975, at the time of the *Trace Center National Workshop Series on Non-Vocal Communication Techniques and Aids*, it was customary to speak of the various aids as 'alternative' methods of communication. Following one of the workshops, as one of the presenters, I questioned the concept of 'alternative'. I noted that most children have some means of communication which we should help them develop and encourage them to use rather than rely completely on an alternative communication technique. Gregg Vanderheiden, the organizer of the workshop series, responded that we should focus on *augmenting* the child's personal method of communication rather than supplanting it with an alternative method. Thus, the term '*augmentative*' communication was born.

Children seem to be born with a drive, need or desire to communicate.

There were many reasons why we might neglect to help as a child develops and uses his or her own communication system. We tend to expect people to use conventional speech or gestures in communicating with us. When their vocalizations are not readily intelligible or their gestures not readily discernible or easily understood, we often conclude we need to develop another mode of communication. We overlook the child's efforts to communicate in our concentration on developing the skills needed to use a communication

aid. The time required for helping a child to develop these skills may leave little time for working on the child's own vocalizations or gestures. Further, teachers and therapists find it more interesting to work with hi-tech devices than to struggle shaping vocalizations knowing that only poor approximations to word pronunciation can be achieved. It is very important however that the child's efforts to communicate be recognized and given an appropriate response. Most adults know the feeling of frustration that arises when we have difficulty making someone understand what we are saying. Think of the on-going frustration experienced by children whose efforts to communicate are usually ignored or not understood. This repeated negative reinforcement has a devastating effect on the development of self-esteem.

The following are some guidelines for those who work with children who have not developed 'normal speech'.

Expect that every child tries in some way to communicate.

Infants communicate long before they learn to say words with conventional pronunciation. The baby cries to signal hunger, discomfort or tiredness. Turning the head away from the mother's breast or from the bottle communicates "I've had enough". Smiles, coos and early word-like vocalizations tell mother that 'all is well'. All these pre-speech behaviours carry meaning to which caregivers respond thus giving positive reinforcement to the child's

communicative attempts. Children seem to be born with a drive, need or desire to communicate. Even where they can't speak intelligibly, they will find a way to impart their meaning or intention. The word 'communicate' is derived from the Latin root which means 'common'. To communicate is *to impart, to share, to make common* one's thoughts, feelings questions, needs, and desires. Some form of communication is the key to entrance into the community and is essential in maintaining one's well being. Aids, whether augmentative or alternative, are not always available to the child when the need or desire to communicate arises. At such times, especially, it is important that the child's primitive or idiosyncratic communication system be recognized and receive prompt response. These early-developed behaviours continue throughout life and constitute the individual's primary communication system.

Look for behaviour that might signal communicative intent.

Several years ago, I was asked to see a ten-year-old described as a passive recipient of care who seemed to make no effort to interact with his environment. While I was talking with his teacher and therapist, I noticed that he was staring fixedly at a cup left on the table. When I asked him if he wanted a drink, he almost jumped out of his wheelchair. After he was given a drink, he continued to stare at his cup. He was communicating that he was still thirsty. Later, when his attendant told him she was going to take him back, he turned his head away and refused to look at her. I noticed that when we heard a noise outside, he kept looking at the window so I pushed his chair so he could look out. As soon as he saw that the noise was being made by men working outside, he was willing to allow his attendant to take him to his room. Was he passive? *No!* Only limited.

Teach those close to the child to understand his/her speech.

It seems that even for the least intelligible child, there is always someone — a parent, sibling, friend — who knows what the child is saying. They have learned to interpret the speaker's word approximations and use context clues. A phonetic analysis of the child's utterances and the interpreter's translation may be used to teach others — attendants, teachers, therapists — how to understand the child. This approach requires a shift in focus from concentration on changing the child's speech to training listeners to interpret the child's speech. It can be done.

The word '*alternative*' suggests that one is offered a choice of two things either of which but not both may be chosen. Our goals should always include improving the child's use of their natural communicative behaviours rather than replacing them. Let's reconsider the idea of '*alternative*'. §

The Evolution of Augmentative Communication

MARGARET SZILAGYI



Margaret Szilagyi

Margaret Szilagyi is the Occupational Therapy Coordinator for Participation House, Hamilton & District, Ontario, Canada, where she has worked for over 15 years. Participation House is a residential facility for 38 adults with severe physical disabilities, eight of whom are currently using AAC systems. As Margie says, "She has a keen interest in the pursuit of excellence in supporting AAC users' goals."

When I reflect back on the evolution of augmentative communication it strikes me how closely it resembles the evolution of man, except of course in terms of the lightning speed at which augmentative communication has developed. Whoever heard of the term "AAC" (Augmentative and Alternative Communication) prior to 1970? I am sure people without functional speech existed. I am just not sure where, for they certainly were not in the 'main stream'. Yet in under 30 years, non-verbal people have accomplished what it took the rest of us — from Australopithecus to Homo-Sapiens — four million years to accomplish.

This type of rapid development doesn't occur without generating some

real challenges, both in terms of maintaining this pace and in terms of bringing everybody up-to-date with the technology. Fifteen years ago I wouldn't have been surprised to have people referred to me who had tremendous potential but 'Neanderthal' opportunities. Generally speaking, once you give them the 'secret of fire' (i.e. a way to communicate) they run with it. But it never ceases to amaze me that I *still* have clients referred to me with no or very primitive means of expressing their needs. Where have you been for the past 20 years? The dark ages appear to

be alive and well in the 90's. Yet equally so and at the same time I am confronted with a generation of 'computer wizards' whose expectations are that we set and confirm our appointments by email. So here lies my dilemma. Like man, not all clients evolve at the same time or rate. They vary based on their early teachings, ongoing environments, and personal capabilities. However, unlike man, these clients co-exist with other non-verbal clients at very different stages, who, with the rest of mankind are preparing for the dawning of the 21st century — *ready or not.*

Client-centered practice compels me to treat each client individually with unique needs, wants, and historical perspectives. But often, where they have been prior to this referral sometimes at the ripe age of forty, is quite unclear. This profile is critical if I am to offer the client options that are consistent with their point in evolution. I need to recognize that not every client comes to me as 'modern man', but rather at different points along the evolutionary timeline. This in turn, impacts on their therapeutic choices.

§

	AUSTRALOPITHECUS	HOMO-HABILUS	HOMO-ERECTUS	HOMO-SAPIENS MODERN MAN
REVOLUTIONARY PERSPECTIVE	• primitive sphere of knowledge/resources • needs to communicate with very few people • verbal 'role models' do not exist	• expanding need to communicate with others • primitive communication based on pictures • complex thoughts/feelings cannot be drawn • limited ability to use outside 'tribe' due to lack of consensus on standard system	• great enthusiasm and urgency to develop skills • increasing standardization of system • more easily used with other 'tribes' • verbal utterances join the written language • developed intellectual curiosity	• ease in verbal and written output • compliant receipt of the marvel of "communication" • high expectations • usable with a wide variety of people
CONSUMER PERSPECTIVE	• may not realize they are non-verbal because family understands them • no speech • communicates with gestures, grunts • no written communication	• dependent on others to identify, direct and motivate use of system • initiated by facilitator • limited ability to use with those unfamiliar with system • limited vocabulary	• eagerness abounds once methods have been found • communication initiated by consumer • standard display based on increasingly arbitrary parameters (less reliance on pictures) • usable with a greater number of other people • increasing ease of system use • progressing to voice output	• ease of verbal and written output • compliant receivers of the marvel of communication • high expectations • usable with wide variety of people

ALDA STEPRANS & STEVEN HANLON



Steven Hanlon

This article is the result of an ongoing discussion I have been having with food-loving Steven Hanlon. Steven lives in the chronic care hospital I work in. He is 36 years old. About 10 years ago, he found out that he has Huntington's disease. Last winter he came to live in the hospital, where I was attracted by his boyish, charming smile and his ability to turn everyone's mood into a good one. Steven has a talent for seeing what is important in life, for being very patient, for seeing the humour in a lot of life's unique situations. I find the story of his life interesting, because as is often the case, it is the story of how one person's life influences the lives of so many others. Steven has had a tremendous impact in teaching the staff and other residents at the hospital about how wonderful living is!

Steven grew up with three brothers and a sister. His first decade was not very unusual. He says that he was a little mischievous and naughty and very

active. He had a special love for fishing, track, hockey, soccer and football.

Steven's dad died of a burst blood vessel in his brain at 47 years of age. Steve was a teenager at the time. The death was hard on him. Steven has fond memories of golfing with his dad and especially of a golfing trip down south with his father and brother, Keith. Steve says that after the death, his mother took good care of them all, even of his grandmother who had had a stroke and was living with them. His grandmother was great and would spoil them all, but still, Steven missed not having his dad around. He continued to be busy with sports, eating and growing up.

If I had a wish, I would stop the wars!

When Steven was in his 20's, his mother died of cancer. This was another tough time for him. But, life went on. He married his beautiful wife, Kim, and he worked as a welder and a shipper on an assembly line at American Motors in Brampton. He was happy with his life. When Steven was 22, he noticed that he was dropping things frequently and often falling and off balance. At 28 he was diagnosed with Huntington's disease. It took a long time to make the diagnosis and it was a surprise, because no one else in his family had had Huntington's. This disease is genetically inherited from one parent who has it. Both of Steven's parents had died young, before they had exhibited any symptoms. Neither his brothers nor sister have Huntington's disease although they had a 50% chance of inheriting it.

During his 30's, Steven has lived with the effects of Huntington's. He spills things easily, falls, has difficulty talking and chokes when he eats. This has all been very hard on Kim, too. It became so difficult and so unsafe for Steven to be at home that he had to come to a chronic care hospital to live. Steven would choke when he ate and he still loved eating! He was losing weight, because his involuntary movements took a lot of extra energy. He was falling too often.

I asked Steven what he wanted most to tell people about his life. He told me a story about how one day, when he was out walking, a policeman stopped him, thinking that Steven, because of his unsteady gait, was drunk. He did not believe that Steven had Huntington's disease and did not treat him well or try to understand him. That made Steven feel very hurt. He wants people to try to understand him.

Over his 30's, Steven's health, especially his muscle coordination, has deteriorated. He can still walk with two people helping him, but usually uses a wheelchair to get around independently. He handles it well. He is sad that he cannot participate in sports the way he loved to before, although he really enjoys watching them on TV. Last year his father-in-law took him golfing and that made Steven ecstatic! They had a wonderful day together. Steven tells me this with sad overtones, because his father-in-law recently passed away. He had been a great source of support.

Because of the trouble Steven has coordinating his muscles, he chokes a lot when he eats. Steven says that what he misses the most being in the hospital are his everyday visits with

his superintendent. They would share coffee and doughnuts every day. Steve's favourite food is pizza, but he loves all kinds of food — Chinese, MacDonalds. Steven admits that he loves the food at the hospital, too. It is specially blended to just the right texture, so that Steve can swallow it without choking. He also gets a lot of it, because with all his jerky movements he uses up a tremendous amount of calories. Steven says he is glad that he has gained some weight now. He gets to eat all the ice cream he wants.

What Steven likes least about the hospital is the noise. He says he otherwise really likes it. He loves the three-wheeled bike in the physio department. He gets to ride it outside in the garden. Steven is also very fond of the Activities Department. People there have time for him. He loves playing Wheel of Fortune on the computer and has a record score of 14,000 points. He also enjoys painting there.

Steven realizes that he is difficult to understand when he talks. He goes to speech therapy and that helps a lot. He is learning to take a deep breath between words. He has a communication board, but prefers to try to get the words out verbally. Again, because of the difficulty with muscle coordination, the saliva in his mouth and throat build up when he talks so he often finds himself choking or drooling. It helps that he is very persistent by nature. He is willing to repeat himself and will often spell the words I don't understand.

He doesn't particularly like to use a letter board to communicate. He says that is because he is stubborn and wants to keep talking for as long as possible. He feels that the best way people can help him communicate is to have patience. He says that the staff in the hospital are really pretty good and usually understand what he wants. He says he seldom feels angry or sad, although recently, when his wife's father died of

cancer, he was very sad for a while. He enjoyed his father-in-law very much and the death also brought back memories of the deaths of his mum, dad, and grandmother. He loves it when his family visit and they can sit out in the garden and talk.

Steven admits that he doesn't know what his future will bring. He worries about his health, about what will happen when his health deteriorates even more. Each person with Huntington's disease is unique and it is hard to know how the illness will progress. He says that he is afraid of death.

Steven finished our interview with one, very clear statement. He said, "If I had a wish, I would stop the wars!"

The conclusion of this interview with Steven shows just how special he is, for even with the opportunity to tell others about himself, his troubles, his pains, he focuses on the world, on those around him. Perhaps, that is one reason people enjoy caring about and for him so much!

§

AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

*The Official Journal of the
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Editor: **David R. Beukelman**, Professor of Communication Disorders,
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Nursing Over the Decades

ALDA STEPRANS



Alda Steprans

When I was asked to write about how nursing has changed over the decades, I became excited at the prospect of sharing with you the many exciting advances in my profession. When I started to write, I understood that the subject was much more complex than I had anticipated it would be. In a sense, it even warrants a book rather than an article. I also found that it was difficult to look at the subject impartially. Probably this is because I care so much about nursing, a profession that offers so many interesting fields to work in, opportunities to expand one's knowledge, chances to meet and know so many people. The responsibilities and challenges continue to awe me, even after all these years.

Recently, Shirley McNaughton and I went to visit Brian Pamplin in the intensive care unit of a Toronto hospital, where he had been readmitted because of problems he was having with his breathing. Brian, for any new readers of this magazine, has been a contributing editor to **Communicating Together** this past year, sharing with us his experiences in a world where multiple sclerosis has affected his ability to communicate. I had worked in an intensive care unit some 20 years ago, so while visiting with Brian I couldn't help but notice just how much computers do in the hospitals now, how they make life more comfortable for patients. When I worked in the intensive care unit, we had to stick patients with needles often, to take blood samples that showed whether there was adequate oxygen in the blood and to check if the components of the blood were balanced. We woke our patients at least every hour to check their blood pressure and pulse. Now, the computer does all this, through one little probe placed on a finger! Technology has strongly influenced the way nurses care for patients.

One thing, however, has not changed. Throughout our visit with Brian I remained acutely aware of the same problem I had encountered those 20 years ago. Brian had no efficient way of communicating with staff. He could lip talk well. But lip talking is so very energy and time consuming that he could only communicate his most basic needs. I know Brian had so much to say. I

felt powerless to truly understand and communicate with him. Brian did have an ETRAN (eye gaze) board, but as is often the case, it had not accompanied him to the intensive care unit. The board may not have given Brian the opportunity to express himself freely, because he was very weak physically, but it may have helped him to clarify some things that were most important for him to say. Wouldn't it be wonderful if in the future computers could help people, like Brian, in intensive care units express their needs and feelings!

Although technology has influenced the way we care for patients, caring remains the essence of nursing. That is the one thing in nursing that has not changed since even before the days of Florence Nightingale. One of the most important tools that we use in that process of caring is communicating with our patients and their family members. Both verbal and nonverbal communication help us to assess our patients' needs, feelings and whether our care has been effective. Magazines, such as **Communicating Together**, are also a valuable tool in communicating with people who have disabilities and are willing to share their experiences and opinions.

What are some things, other than technology, that have changed in nursing over the decades? Education has been important to nurses over all the decades, but it is only in this last decade that nurses in Canada can obtain a Ph.D. in the field of nursing itself. Nurses, other health professionals and society have realized

that the art and science of caring for people is not as simple as it once seemed to be. Health care issues are more complex than ever before. People are living much longer, healthier lives. People who have chronic illnesses are living longer and their needs, physical, emotional and social must be met, in ever more complex ways. Nurses are also coming into contact with more complicated ethical issues on a daily basis. One of the issues in which I am most interested is that of quality of life, a term we often use, but one, which is really quite complex. As we keep severely ill people alive for very long periods of time, how do we assess their qualities of life, especially if they cannot talk? How responsible should nurses be in the evaluation of that quality? How can we best use the information we obtain about someone's quality of life?

Increased knowledge has changed the way we treat certain chronic illnesses. Many of you may remember meeting Bruce Cornish and his mother, in a recent issue of **Communicating Together**. Bruce has Huntington's disease (HD). Until recently, it has been, and in many places is even now, treated as a psychiatric illness rather than as a neurological one. An increased understanding of how the neurological changes that occur in HD affect life has had tremendous implications for how these people are cared for. Not long ago these people were admitted to psychiatric institutions, restrained and over-medicated to keep them calm and free of danger. Now we recognize that much of their behaviour is based on neurological changes and on fear. Many behaviour problems can be treated by giving these people time to communicate and express choices, by treating them with respect, by using

medications carefully so that sedation is kept minimal.

One recently admitted resident who has HD and cannot communicate well verbally, would hit out and try to hurt nurses when they came to wash her in the morning. We understood that she might be afraid that we would hurt her. She had been restrained and roughly treated previously and was understandably afraid that the same would happen again. She had to be approached calmly and gently. Initially, giving her a mild oral sedative an hour before care, helped her relax enough to learn that nurses would be gentle in their care. Before any procedure, she would be told, well in advance, if possible, about what kind of care the nurses would like to give and when

**Although technology has
influenced the way we care
for patients, caring re-
mains the essence of
nursing.**

that care could be given. It was noticed that she was more agreeable to being washed after lunch than in the morning and the nurses were flexible in letting her choose the time for her wash. If she said 'no', that no was and still is respected, even in terms of taking medication (as long as of course, the nursing staff are not being physically harmed and she herself is safe). The 'no's' are much rarer than they used to be. As we have come to know this woman, we have learned that it helps to approach her with a sense of humour. She loves to laugh! We have, over time, come to know her as a person, who has choices and preferences.

Politics seems to be having an increasingly large influence on nursing as health care becomes more and more big business. Many

nurses are losing their jobs and being replaced by less-trained, less expensive workers. Although nurses are more involved in politics than ever before, they continue to be aware of how little say they still have about health care, despite the fact that they are the most numerous of the health care professionals. Doctors and politicians wield all of the power. Nurses have become much better political lobbyists than ever before, but still too rarely get involved in the decision-making processes. I am guilty of this myself. We have a tradition of feeling and acting powerless.

Writing this article has been more difficult than I had anticipated it would be, partly because in the two decades I have nursed, my own understanding of what nursing is has grown and changed. It is difficult for me to write about how nursing has changed without interjecting my own biases. Certainly, the incredible technological changes permit us to care for our patients in more efficient, less invasive ways. Yet, the most important things about nursing have not changed. It constantly amazes me about how much skill, knowledge, communication and patience caring takes. I wonder whether I'll ever truly master the art. But, certainly, communicating with my residents and with the many people around me, is helping me to become a more skilled nurse. §

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The International Society for Augmentative and Alternative Communication (ISAAC) offers members reduced rates for its affiliated journals: **Communicating Together**, **Communication Outlook** and **Augmentative and Alternative Communication** (the AAC journal).

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From Teens to Young Adults

TRACY SHEPHERD

*Tracy Shepherd is a speech-language pathologist at the Children's Rehabilitation Centre of Essex County in Windsor, Ontario. She always brings real issues to the pages of **Communicating Together** and this article is no exception. Tracy's experience does not span the decades, so she has chosen to share her concerns regarding persons who belong to the "The Baby Bust" generation.*

This article touches on some of the hardships teens and young adults are facing when they are graduating and looking at the alternatives available to them when they are finished school. There seem to be few success stories. David Dame is one of them. He has taken the time out of his busy new job to share a few of his thoughts.

This issue of **Communicating Together** focuses on the differences between each decade of individuals with AAC needs. Since I've been in the field less than a decade myself, the stories I have to share relate to consumers in their teens and early twenties. I will leave the talk of other decades to editors with more experience and who have seen change over the years. The children's treatment center at which I work continues to have a segregated school setting, one of the few left in Ontario. It is an interesting and unique experience seeing both sides of the coin which Paul touched on in the last issue — dealing with segregated versus integrated living.

Laurie

Two clients whom I think fondly of are beginning to see the hopelessness of what may or may not be out there for them when they "graduate". Laurie is an 18-year-old who is non-verbal. She communicates very effectively with familiar communication partners. However, she is reluctant to engage in conversation with strangers. Most of her modes of communication are quite slow and her confidence in herself and in unfamiliar communication partners wains. She had been attending school at our center since she was very young. At the age of 18, she decided that going to school was not important to her and so decided to stay home. I continue to ask myself and Laurie, why?

What is out there for such a physically involved girl who has tremendous difficulty interacting with strangers? She currently resides in a foster home and does her own schooling program at home. About once a month she comes into the center to be a guest speaker in a group I am running with young girls learning how to scan. Laurie uses a Lighttalker to communicate and acts as a good role model for these new AAC users. She really feels like she has something to offer these youngsters and I can see her confidence and self esteem grow. But what else is there? I don't understand why she doesn't feel more helpless about the situation unless it just hasn't hit her yet. Being a children's treatment center, the funding doors are closing on us everyday. We soon may not be able to provide the support to young adults which they need once they have graduated. Now we can only steer them to a very few options in their communities that are available. Sheltered workshops are closing. Group homes are full with lengthy waiting lists. Social programs rarely exist for these individu-

als to get out and just interact with their peers. They used to be able to do this in school. What happens when school is over? How will Laurie occupy her time and feel like she is contributing to society? And what was the purpose of hours and hours of learning to communicate with a high technology system if there is no one for her to talk to out there? I'd like to think that it isn't really as hopeless as this, but help me out!

Frank

Another AAC user who has begun the struggle is 17-year-old Frank. Frank attends our segregated school setting and desperately wants to be integrated into a high school. His family is very reluctant to have him go out because they feel he cannot communicate well enough. He also uses a variety of modes both light and high tech. I feel he will never know if he can communicate sufficiently if he doesn't ever try. Giving him the social interaction at this age would be an experience he would not soon forget. Teenagers need this social interaction. It would give him an opportunity to learn on his feet about how to use all of his modes of communicating to get by in the real world. We all remember how real world high school can be. But after high school...where will he go?

David

This next story is a definite success. Unfortunately the successes seem to be few and far between. My friend David is 25-years-old and recently graduated from the University of Waterloo with a degree in marketing. David has cerebral palsy and his speech is quite intelligible. This has been his saving grace. He is proud to have landed a job in his field in his own community but only after a painstaking year of pounding the pavement.

He discussed with me how staying at home for the year became quite depressing for him. David sees a lot of the difficulties a disabled person might face but probably not half as many as a speech impaired individual. He requires assistive devices for writing and uses a wheelchair or scooter. Is it because he can communicate by conventional means that he gets a job and others with the same potential remain out of work? What is the answer? David has shared some of his thoughts about his new job in the following piece titled "Get a Job!"

Many other young adults haven't been as lucky as David. I've seen many of them at home or in group homes with not many options available to them. So what are we doing anyway and why are we doing it? What are we training individuals for in the long term? What is out there for AAC consumers? As Nola Millin mentioned in the last issue, are we giving them false hopes? Maybe we are, but we have to give them something. We can give them the tools to be able to communicate and go out into the community and

function in society. Only society can give them the opportunities to use what they have worked so hard to learn.

§

Get a Job!

DAVID DAME

The old cliché, "Get a Job" is one of the most difficult tasks facing college or university graduates today, even harder if you have a disability. With global competition, companies have to be more efficient, productive, and intuitive. They look for the impact people can make that can bring immediate results. The biggest

If there is any advice I may give it is just never give up.

difference between post-secondary school and the labour force is the train of thought. In post secondary school they will tell you everything they have to offer you. In contrast employers want to hear what you

can offer *them*. Even though there is employment equity, most employers are still skeptical. They are concerned with possible structural costs to their office, how you will interact with their present staff, and whether or not you can do the job as well as the other people applying for the position. When I graduated it took me about a year to land my first permanent position. I sent out numerous resumés but had little response. (It was not the disability but the economy.) I volunteered my time to build experience and someone at the company I work for now noticed my abilities more than my disability. This person gave me the opportunity to prove myself to the workplace, my fellow employees, and most importantly myself. Since I have started my self confidence has come back as well as my self esteem which was slowly decreasing after the frustrating year of job hunting. I can never thank that person enough for what he has done for me. If there is any advice I may give it is just never give up.

§

CONTEXTS

Time Flies or One Generation of Difference

GEB VERBURG



Geb Verburg

A generation, (or some 20 years) ago, I began to work at the Blissymbolics Communication Institute (BCI) to analyse data from a survey of Bliss symbol users. I had little or no experience with Bliss symbols. Although I had studied child and developmental psychology, I had very limited experience with children with physical disabilities, their parents, and service providers. This article is a personal retrospective relying heavily on my own perspective on what I think has changed and what has not changed since I started to work in the field of Augmentative and Alternative Communication and rehabilitation. I want to write about what I think have

been: "three major changes" and "three major non-changes" that have and have not happened.

The positive changes that I want to highlight are: (1) the establishment and recognition of the field of AAC; (2) the growth of empowerment and advocacy; and (3) the increasing expectations and growing independence of people with communication impairments. For the things that, in my opinion, have not changed I am choosing: (1) the employment rate for people with disabilities; (2) our service model, whether this is a medical, functional or societal model. While on models, I want to look at our research model, which also has not changed significantly in the last 20 years.

AAC: A New Field

The late seventies and early eighties were interesting times because a lot of new things were created for a population that was in a sense discovered and defined. At the same time new tools and technologies were being developed. Blissymbols were among the forerunners of the new language tools. Instead of using orthography, sign language, Morse code or Braille, Blissymbols use images, pictographic or abstract symbols that express meaning and can be combined to form new words or sentences. This was a departure and a breakthrough for a number of nonspeaking children. It is no coincidence that a number of picture and pictographic systems emerged in quick succession. In addition to the new communication vehicles, personal computers were being introduced at that time and the marriage of a communication system and (portable) computer became a realisable dream. Those computer-based portable speaking tools are now a reality and will continue to evolve a bit more yet. Part and parcel of the new augmentative language systems, the new technology, the new definitions, was the need to create an entirely new field with its own name (AAC), its own journal, and its own professional organisation — the International Society for Augmentative and Alternative Communication (ISAAC). Add to this the creation of faculty positions, funding rules, and laws that secure accommodations and /or adaptations for people with disabilities —including AAC related disabilities — and you too will be awestruck by the massive changes that have taken place in Augmentative and Alternative Communication over the past 20 years.

Empowerment & Advocacy

These are the two pillars of independence. On the one hand, parents and clients must be given (offered, led to) power to make decisions for and by themselves. On the other hand, professionals must surrender some power or rather vest power in the clients and

families. The centre at which I work has had a “client advocate” for several years now. We also have a Family Advocacy Resource team and a Family Advisory Committee. The Ontario Rehabilitation Technology Consortium has Consumer Advisory Panels with every major research and development team. In spite of all these very positive changes, there still appears to be a long way to go before every parent or caregiver of a child with disabilities has all the services and supports that they need from the very beginning to the point of the young adult’s maximum independence.

It is, therefore, still necessary that we, professionals, friends and families continue to advocate for the rights and needs of nonspeaking children and of all children for whom society still contains too many obstacles.

Expectations of Independence

Twenty years ago, much more so than today, a nonspeaking child was almost automatically funnelled into a low-demand, low-expectation educational stream. The expectation of a nonspeaking child ever to hold a job was virtually absent. This expectation has changed very much. Schooling for employment or a preparation for higher education is perhaps not yet 100% accepted but is much more common. As much as I want to emphasise the importance of the pursuit of higher education, I think we should also keep in mind what Nola Millin pointed out in the preceding issue. Perhaps schools should spend more time teaching young people with disabilities how to fill their time in satisfying and productive ways in case they are able to get only a part-time job or maybe no job at all. I consider our progress in the area of realistic expectations and planning for independence, positive overall, although the practical opportunities for gainful employment for nonspeaking people still leave a lot to be desired.

Employment Rate

The employment rate for people with disabilities (from 30 to 67%) is still very far below that for people who do not

have a disability. One of the few uplifting statistics in the 1991 national Health and Activity Limitations survey carried out in Canada was that people with more education have a better chance of getting a job. This applies both to adults without disabilities who have university degrees (87% are employed) and to adults with disabilities and a university degree (67% are employed). It is too bad that even this somewhat more encouraging employment climate still shows a 20 % spread between people with disabilities and the general population. The other bad news is that the same survey reported that the percentage of persons aged 15 to 64 with disabilities who have completed a university degree is less than half that for persons without disabilities in that same age bracket.

Service Model

Over the past 20 years, we have moved away from a medical model approach to the treatment of disabilities. This I think is a considerable improvement. The medical model may be very appropriate for a patient whose life is threatened or in serious danger. It is not a suitable model to help children attain greater independence. We have, however, not yet managed to find a more appropriate, agreed-upon alternative to replace it. In the interim there is much talk about models, much disunity and not a very clear and unified approach that is offered to the parents and clients who are now using the services.

At present, there are two serious candidates for an alternative model to replace the medical model. One is the *societal* service delivery model. In this model, service delivery is based on the belief that disability is caused or engendered by the way society is organised. That is, disability is caused or aggravated by the absence or lack of societal accommodation to people with disabilities.

The second candidate is the *functional* model. This model does not approach service as a process guided by the “diagnosis of the patient” and the corresponding treatment pattern and

expectations. Rather it looks at the functional abilities and needs of the client and strives to enhance the functionality of each client. It appears to be easier to align the goals of the clients and parents with those of the therapists and other professionals within the functional model.

The *societal* model is one that I still fail to grasp in all its significance. It appears to me that the societal model represents a rather simplistic switch of culprits in the situation. The early medical model placed all the "blame" or onus of the disability on the medical condition and, through that, on the child who happens to be the carrier of that (unpleasant, bad, crippling) medical condition or on the parents). The societal model of disability places all the blame on society. Simply identifying society as the generator of the state of being labelled disabled may be true if you choose to believe so. On the other hand, it may equally be false if you choose to believe differently. Blaming society for the existence of disabilities has a temporary shock value. I'm afraid, however, that it does not have much use beyond that.

What do we need instead? Or perhaps: Do we need a model of service delivery at all? Probably for the time being, the answer is Yes. However, the entire concept of a "model of service delivery" presupposes that there are people who deliver services and people who receive services. Giving and receiving are terms that denote a status difference. The giver has something to give and the receiver (must or ought to accept, or just) accepts what is given. In the case of rehabilitation services, the receiver can not turn around and become a giver. Nor does the giver, in ordinary circumstances, turn into a receiver. There is therefore an inequality in the entire notion of "service model", an inequality which will skew rehabilitation services and thus subvert the independence of people (children, young adults, adults and older persons) who must be recipients of those services.

The only equalisation that I can think of is the situation in which people buy rehabilitation services from whomever they want for whatever they deem the services are worth. In this way rehabilitation services become like a product that people can go out and purchase. Of course this means that the funding structure of health care must change to accommodate this kind of organisation. The places that now provide rehabilitation services must also change in order to be able to market their services as the best and most cost efficient services in town. Once that happens, we will have arrived at a totally new model or version of service delivery, namely that of the purchase of services. I think this is going to happen sooner than we think. I believe that we ought to think about some of the positive but also about potential negative effects of this new way of working.

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that we — professionals,
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Research Model

We are not accustomed to thinking of research as following a model of one kind or another but it does of course. Research is not just scientific, observational, and/or empirical. It certainly is not objective in the sense of being value-free. There are no "value-free" or "value neutral" activities. Perhaps a distinction could be made between research that primarily enhances the pursuit of knowledge (or a researcher's career), and research that aims to solve real (clinical, technical or practical) problems. Research can be methodologically sound or unsound. It is useless to carry out research that is methodologically unsound

through poor design, poor or illogical questions, poor sampling or bad or wrong measurements or analyses.

However, assuming that research is sound there are still a number of directions or paths one can take. Generally, research can serve the status quo or it can advocate against it or against part of it. Participatory Research (PR) and Action Research (AR) have traditionally been directed at resolving "perceived wrongs" that existed within the status quo of a society.

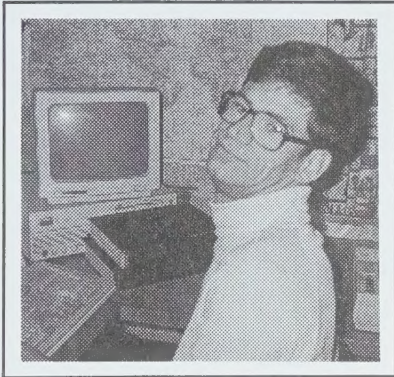
Methodologically sound research has often stopped short of carrying its results through to applications in society. It was for example normal to study childhood powered mobility, find that powered mobility is very beneficial to children with mobility impairments and go no further than report these results at conferences and in scientific papers. Today I would ask: "If I find a technology that has a beneficial effect upon a child or adult's life and development, can I justify not advocating for the adoption of this technology by our health care system, given that it has no detrimental side effects and does not get sold at more than fair market value?" My answer, now, would be: "No. I cannot let the results of my research merely appear in print or just be heard in lectures and presentations. If the results are important enough, then it is incumbent upon me to do my utmost for these results to be acted upon by relevant authorities or agents."

For me that means that my research plans become expanded to go beyond the normal sound research practices and the reporting of results, to also include a detailed plan on how we can and must advocate for action based on the outcomes of research (provided of course the work is valid and adequately confirmed). In this way a researcher must become more proactive in the follow through of his or her research outcomes. This means more planning, longer projects, and implies that researchers have to start playing a much more direct advocacy role.

§

The Generation Looking Glass.

PAUL MARSHALL



Paul Marshall

When I look back at different events throughout my life, it is very clear that our society is moving toward viewing anybody with a disability more as a norm. At least this is a feeling that I get living in a western culture. Sure there will always be those looks, mind sets and words to make us realize that it will be an up-hill battle all of our life as we try to live as normal a life as we can. But is this not just a creed of living?

I have been very blessed to be able to travel overseas and help with several AAC presentations and learn from other cultures. No doubt, these trips made a huge impact upon me. I personally feel it is unfair to try to measure what could be viewed as positive or negative, without taking into account a number of factors. We must do this before we can or should try to bring about change. I can remember reflecting back upon my early memories of going to a Cer-

ebral Palsy Center. The thing that sticks out in my mind is those black and white hallways. Looking back, it almost seems those black and white hallways were a statement from society at that time. There wasn't much gray area and certainly no coloured areas when it came to having some kind of a life that was meaningful. The culture just didn't have the skills, knowledge, technology and the resources that we have at our finger tips today. Many places around the world are struggling to bring into reality some gray, some coloured areas into their cultures so the disabled population will have some opportunities. I will be the first one to say, without the large number of people who have worked hard to bring around many opportunities in Canada's culture regarding integration and inclusion, my life would be radically different. I wouldn't have been blessed beyond measure to be allowed to grow up and live in a culture where the opportunities of living a very full, active and rewarding life are available if the individual can access the resources.

If you told me fifteen years ago that, by the age of thirty-three, I would have been on several overseas trips and would be deeply involved in working with Blissymbolics Communication International as well as working part time in the computer research field, I would have thought you were dreaming. As I look at the different stages of development that have happened in the world that allows me today to do the job I do, it is just amazing! Fifteen years ago, technology such as state-of-the-art

computers, electronic mail (email) and the Internet, was just not there for me to use. I am well aware that many people living in South Africa or Israel or in many other nations with the same physical limitations as I have just don't have access to the these kinds of resources. The chances that I have are harder for them to gain. I see the western world as a leader in this area. This however means we also have a great responsibility to go further into research and development. At the same time we have the responsibility to step back and make sure we *all* have as much support as our personal circumstance allow.

When we look at the changes that occur over generations and their impact upon the disabled community and on the whole disabled movement, we can see the following characteristics:

1. It takes time.
2. Change probably will happen because of the work of a small group or groups, not because of a big organization.
3. In order to have change, we have to be "distance viewers". In some circumstances the changes that we want to happen, might not happen in our lifetime. Maybe however, through our lighting the spark, they will happen someday.

The looking glass is great for dreaming. But the real work is done by people like you and me who aren't willing to let our circumstances of today alter tomorrow's visions.

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